The Future of Disability in Alaska Summit & Follow-up Survey

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A Report Prepared by

The Center for Human Development

University of Alaska Anchorage

UAA Center for Human Development
University of Alaska Anchorage

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Executive Summary

The Future of Disability in Alaska Summit was held in Anchorage in the summer of 2013, May 9-10. The purpose was to gather perspectives from a diverse group of stakeholders to inform a vision of the future for people with disabilities in Alaska in five broad topical areas: 1) Housing Arrangements, 2) Advocacy, 3) Relationships, 4) Economic Wellbeing, and 5) Health. It is acknowledged that there are many very important topical areas that should be examined in this type of forum. The limited time for this summit required making some choices and focusing the discussion.

About 76 stakeholders participated in the summit including people with disabilities, family members, advocates, service providers, policymakers, and others. A follow-up online survey was conducted to gather information from a broader range of stakeholders and to get a sense of the highest priorities in each topical area. There were 285 survey respondents. In addition to other overlapping roles, about half were persons with disabilities or family members, and about half were service providers.

The purpose of this report and other products coming out of this effort is to inspire stakeholders to periodically reflect, individually and in groups, on how they are working toward the vision in a relevant topical area and taking action in the context of advocacy, policy/regulation, funding, and services/resources. Please see the body of the report for full elaborations of the vision for each topical area, and the many suggested strategies to accomplish it.

What is the vision of the future for Housing Arrangements?

The vision for quality housing incorporates affordability, stability, safety, integration, choice, accessibility, and well-trained staff. Inclusion is interdependent relationships characterized by respect, appreciation, support, and belonging. The vision calls for personal choice and access to supports with diverse options in both urban and rural areas, flexibility in funding and supports, and the right of individuals to have a meaningful voice.

The first priority is for 1) *affordable, stable housing in safe neighborhoods*, followed by 2) well-trained staff and consistent services. The following were each endorsed by 46% of respondents: housing in a community of choice that respects independence, freedom, and culture; flexibility in funding and supports; and individuals have a meaningful say in activities, routines, and who lives with them.

What is the vision of the future for Advocacy?

The vision for advocacy includes public awareness, greater accessibility, and inclusion as a respected member of the community. The vision calls for a strong self-advocacy system, safe places and support to learn self-advocacy, and leadership roles. It calls for unity in advocacy and collaboration, greater involvement in civic engagement and policy development, and greater awareness and equality in the legal system.

The priority that rose to the top is 1) the *choice, desires, and opinions of individuals are valued and respected*, followed closely by 2) greater public

awareness and accessibility, and 3) unity in advocacy across agencies, types of disabilities, and the lifespan.

What is the vision of the future for Relationships?

The vision for relationships is a society that takes it for granted that people with disabilities have the same human needs and desires as people without disabilities and the same human rights. It includes safety and inclusion in social environments, and access to relevant education and supports. The vision calls for the same rights to make choices as people without disabilities, and the removal of barriers to healthy relationships imposed by policy and regulation.

The top priority is 1) *safety from abuse, violence, unfair treatment, and exploitation*. This is followed by 2) flexible supports driven by individual needs and priorities; 3) staff respect the dignity of risk, boundaries, and the balance among individual choice, safety, and privacy; and 4) recognition of equal human needs for healthy relationships and equal human rights.

What is the vision of the future for Economic Wellbeing?

The vision for economic wellbeing starts at a young age with the economic stability of families, increasing awareness and capacity of parents, schools, doctors, and others providing services for children. It continues along the lifespan into the expectation for employment and access to the same opportunities in preparation for employment and financial security utilized by other adolescents and adults, resulting in meaningful employment and careers. It extends to financial security for seniors along with options that respect independence and choice in housing, employment, and activities. The vision calls for community awareness and involvement, as well as policy and regulations that support economic wellbeing from the individual perspective without penalties for being successful.

This area was broken into two subareas for setting priorities. The top priority for economic wellbeing across the lifespan is 1) *long-term planning for economic wellbeing across the lifespan,* followed by 2) opportunities to work full-time and earn a living wage, and 3) equal opportunity for job skill development and career exploration. The top priority for economic wellbeing awareness and policy is *no penalties for gaining employment.*

What is the vision of the future for Health?

The vision for quality of healthcare includes more individualized, flexible approaches and greater continuity of care, using a team approach for transition from pediatric to adult services. It calls for improved professional standards, greater accountability, better training, and incentives for health professionals to work with people with disabilities. The vision includes better overall management of medication, with increased access to alternative approaches. It addresses wellness with a holistic approach to an overall quality of life, with more access to facilities, transportation, information, prevention, and resources. To facilitate choice, there is more individual and family involvement in setting goals and making decisions, more education about evidence-based

information, and shared responsibility. The vision calls for strong self-advocates, more family practice providers, and respect for the right of individuals to make decisions about their own bodies. Flexible policies, regulations, and funding support care-driven services, with both standard and holistic approaches, that promote health and integrate healthcare.

This area was broken into three subareas for setting priorities. The top priority in quality of healthcare is 1) *coordination and continuity of care among providers,* followed by 2) providers trained to work with individuals with disabilities, and 3) services are individualized and flexible. The top priority in health and wellness is 1) *a whole person, quality of life approach,* followed by 2) a focus on wellness and prevention, and 3) individuals and teams share responsibility for choices in health goals, plans, and decisions. The top priority in health access and policy is 1) *affordable, quality healthcare,* followed by 2) policy supports care-driven services.

What improvements could have impact across areas?

In working with the volume of stakeholder perspectives gathered in the summit and in the follow-up survey, it became apparent there were issues that crossed all topical areas. These Universal Themes include:

- Transportation
- Inclusion
- Advocacy
- Equality
- Accessibility
- Choice
- Flexibility
- Safety
- Public Awareness

It can be concluded that considering the above issues and making improvements whenever possible could have broad impact. Please see the full report for a discussion of how these issues came up under each topical area.

Reflection Questions

In any topical area…

- How does advocacy support the vision and priorities?
  - If it is weak, how can it be strengthened?
- How do policies and regulations support the vision and priorities?
  - If they create barriers, how can they be changed?
- How do sources of funding support the vision and priorities?
  - If they are in conflict, what other funding can be used?
- How do services and resources support the vision and priorities?
  - If they fall short, how can they be improved?

Introduction

The Future of Disability in Alaska Summit was held in Anchorage in the summer of 2013, May 9-10. The purpose was to gather perspectives from a diverse group of stakeholders to inform a vision of the future for people with disabilities in Alaska. A task force comprised of individuals from UAA and Hope Community Resources planned and organized the summit:

- Herb Bischoff, Hope Community Resources
- Heather Chord, LEND (Leadership Education in Neurodevelopmental & Related Disabilities) Fellow, University of Alaska Anchorage (UAA)
- Michele Girault, Hope Community Resources
- Stephanie Johnson, Master's of Social Work Candidate, UAA
- Karen Ward, UAA Center for Human Development

The format of the summit consisted of a keynote speaker, opening remarks, and a series of presentations by recognized Alaskan leaders in the disability field, followed by working group discussions.

- Keynote Speaker: Katherine McDonald, PhD, FAAIDD from Syracuse University
- Opening Remarks: Steve Lesko, Executive Director of Hope Community Resources

It is acknowledged that there are many very important topical areas that should be examined in this type of forum. The limited time for this summit required narrowing the discussion to five areas. Listed below are the topics that were chosen and the presenters who introduced them.

1. Housing Arrangements: Roy Scheller, PhD, Deputy Executive Director of Hope Community Resources
2. Advocacy: Kara Thrasher-Livingston, State of Alaska, Senior & Disabilities Services
3. Relationships: Karen Ward, EdD, Director of the UAA Center for Human Development
4. Economic Wellbeing: Millie Ryan, then Executive Director of the Governor's Council on Disabilities and Special Education
5. Health: William Browner, MD, Alaska Native Medical Center

Based on findings from a qualitative analysis of the stakeholder perspectives gathered at the summit, a follow-up online survey was designed and implemented. The purpose of the survey was to gather perspectives from a broader range of stakeholders and to get a sense of the highest priorities in each topical area.

Method

Summit

Following each of the five topical presentations, participants in The Future of Disability in Alaska Summit broke into seven working groups. Group membership was randomly assigned at registration. Though there was flexibility to accommodate individual needs and latecomers, group membership remained mostly constant for the duration of the summit.

Facilitators for working groups were engaged prior to the summit and prepared with a set of guidelines for group process. Facilitators were responsible to help groups establish and follow ground rules. They ensured groups chose note takers and timekeepers. Facilitators introduced a pre-established set of questions and helped to keep discussion moving and on topic, but otherwise they did not control the direction of discussion. They encouraged equity in participation, kept a record of off-topic issues, and intervened if necessary when there were conflicts.

Working groups addressed the following questions in each topical area (Housing Arrangements, Advocacy, Relationships, Economic Wellbeing, or Health):

- What is your vision of the future in [topic]?
- Looking at different stages of life, what are your desires/needs to achieve your vision of the future in [topic]?
    - Young children
    - Adolescence
    - Adulthood
    - Seniors
- What do you not want to see in the future?

Qualitative Analysis of Summit Responses

The task force continued to meet after the summit to determine what process would be used to analyze the large quantity of qualitative data collected, and how to garner broader input from Alaskan stakeholders who were not able to attend the summit. Dr. Katherine McDonald from Syracuse University continued to work as a consultant in this process. Three people were chosen to conduct a qualitative analysis along with Dr. McDonald: Dr. Karen Ward, Rain Van Den Berg, and Roxann Lamar from the UAA Center for Human Development ("the analysts"). The original task force reviewed findings and had opportunities to weigh in at the completion of each major step described below.

Step 1: The notes from each of the seven working groups were transcribed from the flip charts used during the summit, and a document was prepared for each topical area combining the responses for that topic across the 7 working groups. Within each topic, responses were organized under 1) Vision of the

Future, 2) Stages of Life, 3) What We Don't Want to See, and 4) Points for Discussion (other). This pattern of grouping responses basically followed the pattern of questions that were asked of summit participants.

Step 2: The four analysts worked in two pairs, dividing up topics to conduct an initial sort of responses into themes that were specific to each topical area. Across themes, responses were further sorted by: 1) Vision, 2) Needs, and 3) Strategies. The sorting of responses went through a primary review by one pair of analysts until they reached consensus, then it went through a secondary review by the other pair of analysts. This process continued until there was consensus across analysts on how responses were categorized and sorted in each topical area. At this stage of the process, all data was maintained in its raw form, but categorizing started a process of interpretation.

Step 3: The four analysts continued the same consensual process with primary and secondary reviews in pairs to synthesize comments into summary statements, the next level of interpretation. Within each theme category in each topical area, the information under Vision and Needs was combined into a series of summary statements. Strategies were combined in summary statements that aligned with themes and vision/needs statements.

Step 4: Two of the analysts continued a consensual process to reduce the Vision/Needs statements as much as possible to series of bulleted phrases representing main ideas for drafting survey items. The draft survey was reviewed by the other pair of analysts and members of the task force, and revised according to their feedback. The draft survey was tested separately by two individuals with I/DD, one who had attended the summit and one who had not. Items were revised for understandability based on their feedback.

Follow-up Survey

The purpose of conducting a follow-up survey was two-fold: to hear from a broader range of stakeholders and to get a sense of the highest priorities. The survey used the five topical areas from the summit. However, Economic Wellbeing and Health each had a markedly larger number of ideas. These two topics were broken into subthemes to make them more manageable in a survey format. This resulted in eight sections for an online survey:

1. Housing Arrangements
2. Advocacy
3. Relationships
4. Economic Wellbeing Across the Lifespan
5. Economic Wellbeing Awareness & Policy
6. Quality of Healthcare
7. Health & Wellness
8. Health Access & Policy

Within each of the eight sections of the survey, respondents were asked to choose what they thought was MOST important from a list of ideas. Usually they could choose up to three ideas from a list, but in two subareas with fewer options they could choose only one or two. Each prioritization item was followed by an opportunity to note any needs that were not yet included. The last section of the survey asked for demographic data to summarize types of respondents and areas of residence. When respondents submitted the survey, they were directed to a separate online survey where they had an opportunity to enter into a drawing for $25 gift cards if they wished.

The survey invitation was sent out on October 15, initially utilizing the listserv resources of the UAA Center for Human Development, Hope Community Resources, and the Governor's Council on Disabilities and Special Education. The invitation encouraged recipients to share the invitation with others, and offered accommodations and assistance through the UAA Center for Human Development. The deadline for response was October 31, but an examination of preliminary results indicated there was not as much response as desired from persons with disabilities and family members. Organizations working with these populations were encouraged to make more effort to get the survey out to individuals and families, and the deadline was extended to November 15.

This report combines the results from both the qualitative analysis process of The Future of Disability in Alaska Summit with results from the follow-up survey. It includes vision summary statements, and also strategies suggested by summit and survey participants that can be considered in making plans and working toward the vision.

Participants

Summit Participants

There were approximately 76 participants in the summit. Stakeholders included people with disabilities, family members, advocates, service providers, policymakers, and other people interested in the future for people with disabilities in Alaska.

Survey Respondents

There were 285 respondents to the online follow-up survey. In demographic data respondents were asked to "check all that apply" from a list of types of respondents. Seventeen respondents skipped this item. Of those who answered the question (n = 268), well over half (160 or 60%) indicated they were persons with disabilities or family members, over half indicated they were service providers (147 or 55%), and almost half indicated they were advocates (129 or 48%). Detailed results are listed in Table 1.

Table 1: Types of survey respondents

Type of Respondent	Number	Percent
Service provider	147	55%
Advocate	129	48%
Family member	114	43%
Educator	57	21%
Person with a disability	46	17%
Healthcare provider	41	15%
Self-advocate	25	9%
Academic/Researcher	15	6%
Policymaker	13	5%
Other	31	12%
Total Respondents	268	100%

Of the 31 respondents indicating "other," 5 noted they were counseling, mental/behavioral health, or rehabilitation professionals; 4 caregivers of persons with disabilities; 4 administrators or government workers; 3 vocational rehabilitation workers; 3 case managers or care coordinators; 2 students; and 2 community members. The rest added clarifications, unique roles, or job positions.

Respondents were asked to provide a zip code for the place in Alaska where they lived most of the time. There were 47 (16%) respondents that skipped this item, and one who gave a zip code for another state. In Table 2, the Alaskan zip codes provided (n = 237) were sorted by the economic regions of the state used by the Alaska Department of Labor and Workforce Development, as compared to the most current general population statistics from the same Department.

Table 2: Regional response profile

Region	Response (% AK zip codes)	General Population (%)
Anchorage/MatSu Region	148 (62%)	392,643 (54%)
Gulf Coast Region	27 (11%)	80,750 (11%)
Interior Region	17 (7%)	115,114 (16%)
Northern Region	5 (2%)	27,312 (4%)
Southeast Region	35 (15%)	74,423 (10%)
Southwest Region	5 (2%)	42,056 (6%)
Total	237 (100%)	732,298 (100%)

At first glance, there seems to be a disproportionate response by region to the survey, particularly an over-representation in the Anchorage/MatSu and Southeast Regions. However, the population of interest for this survey is not distributed the same as the general population. The vast majority of disability services, including highly specialized services are more available in urban areas. There are not only more providers, but it is also a known migration pattern that people with disabilities and their families relocate to larger population centers because they need access to specialized and intensive services. For example, the Alaska Division of Vocational Rehabilitation 2014 State Plan noted that Census data documents a definite rural to urban migration pattern for persons with disabilities in Alaska [see Attachments 4.11(a) and (e)(3) of the State Plan]. With that in mind, the most questionable result in regional distribution of survey respondents is a low response from the Interior Region that includes Fairbanks.

There were 169 respondents who entered their names and addresses into the drawing for a gift card. After the conclusion of the survey, winners of the drawing were chosen using the random number assignment function in Excel. The five entrants with the highest random numbers were awarded $25 gift cards to popular shopping vendors. Gift cards were donated by the UAA Center for Human Development.

A note about comments added to surveys: The intent of adding a comment space after each priority ranking question was to gather any "missing" ideas, especially from people who did not have a voice in the summit. However, many respondents used the comment space to repeat items from the list provided, beyond the ones they chose as the most important. This reflects the difficulty of choosing only a few things when everything is important.

There were hundreds of comments added to surveys and each was checked against information recorded from the summit to evaluate if an idea expressed in a survey comment was already sufficiently covered, particularly in the wealth of suggested strategies (not presented in the survey). In this report, any new information from survey comments was integrated with the information gathered at the summit. A few quotes from survey comments are also included to help remind readers this is about people's lives.

A note about interpreting results for priorities: Anything that was endorsed as most important by a third or more ($\geq$ 33%) of respondents was considered meaningful.

Results are organized in the following sections by topical area.

Housing Arrangements

"I DON'T want to be surrounded by neighbors with mental disabilities…I DON'T want to be surrounded by physically disabled people…I DON'T want to be living near drug and alcohol abusers and dealers. Apart from my need for a safe ramp access to my apartment, I should be fully integrated into a normal community." –Survey Comment

What is the vision of the future for Housing Arrangements?

Quality of Housing

- **Housing is affordable, stable, and in safe neighborhoods.**
- **Housing for people with disabilities is integrated into all aspects of neighborhood and community life.**
- **Housing is in a community of choice, appropriate and accessible for every stage of life.**
- **Housing options truly honor and facilitate choice, independence, freedom, and culture.**
- **Housing services are conducted by well-trained staff; services are consistent without over-regulation, addressing complex medical and behavioral needs.**

Inclusion in the Community

- **Relationships in inclusive communities are interdependent, characterized by respect, appreciation, support, choice, and belonging for all people at every stage of life.**
- **Communities are intentional environments, designed with spaces accessible to all people of any age to learn, play, recreate, and socialize.**
- **Communities are consistently concerned with the safety and wellbeing of all residents, including responding to emergencies.**

Personal Choice & Access to Needed Supports

- **Flexibility in funding and supports accommodates cultural preferences and personal choices at different stages of life, including home ownership, marriage, and aging in place.**
- **Individuals have a right to have a meaningful say in who will share their homes with them and in their own activities and routines, including management of household chores.**
- **Choice in housing assumes that a number of viable options are available in both urban and rural areas, including options for families that need appropriate resources and supports for school, childcare, and respite.**

What are priorities for Housing Arrangements?

The top priority in Housing Arrangements chosen by 78% of survey respondents is for affordable, stable housing in safe neighborhoods. The second highest priority is for well-trained staff and consistent services (58%). Three items tied for third priority, each chosen by 46% of respondents. Table 3 shows the total response.

Table 3: Priorities in Housing Arrangements

Rank	Priority Statement	%Response
1	Affordable, stable, and in safe neighborhoods	78%
2	Well-trained staff, consistent services	58%
3	Community of choice that respects independence, freedom, and culture	46%
3	Flexibility in funding and supports	46%
3	Individuals have a meaningful say in activities, routines, and who lives with them	46%
4	Urban and rural options, including family resources and supports	29%
5	Integrated with accessible spaces to learn, play, recreate, and socialize	26%
	Total Respondents: 285	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

What strategies were suggested for Housing Arrangements?

Strategies for Quality of Housing

- Make safety and stability in housing primary concerns. Ideas:
  - Provide accommodations that facilitate remaining in or moving to communities and neighborhoods of choice
  - Make sure emergency plans are in place
  - Provide more training for end of life and hospice care, particularly for rural areas
  - Increase access to training about nutrition, healthy choices, budgeting, and independent living
- Expand affordable housing options that include persons with disabilities, of all ages and backgrounds, within the community (as opposed to segregated housing).

- Fully utilize universal design and technology resources (e.g., smart homes) to increase independence and accessibility in homes, in both urban and rural areas.
- Incorporate more flexibility in regulations and licensing in order to facilitate choice, personal preferences, and inclusion in the community.
- Utilize creative tools to conduct intentional life planning beginning at a young age and evolving over time to address housing issues in the context of major life transitions.
- Facilitate respectful improvements to language in regulations and services over time, responding to evolutions in language and attitudes.
- Train support staff in housing services to maximize community inclusion for individuals and families, to foster independence in navigating the community, and transition planning.
- Ensure that support staff are paid a decent wage and have the benefits necessary for their own healthy lives.

Strategies for Inclusion in the Community

- Create intentional communities to maximize integration and accessibility.
- Based on individual choice, explore and participate in and/or create spaces for natural community gatherings and other interactions that foster respectful and reciprocal relationships. Ideas:
  - Welcome wagon
  - Community meetings
  - Community improvement projects
  - Block parties
  - Volunteer and service opportunities
- Facilitate community-level exploration of ways to make activities accessible to all community members. Examples:
  - Spaces for children to play
  - Spaces for adolescents to socialize
  - Spaces for community gathering
  - Spaces for sports and recreation
  - Transportation
- Facilitate community-level exploration of ways to make neighborhoods into safe places for all community members. Examples:
  - Neighborhood watch
  - Safety and emergency plans
  - Peer supports
  - Awareness for landlords

Strategies for Personal Choice & Access to Needed Supports

- Reform regulations and policies that inhibit personal choices and preferences in housing services, such as disincentives for home ownership, marriage, aging in place, and multi-generational homes.
- Implement mechanisms to respect the personal preferences of individuals, couples, or families in everything that impacts their homes. Ideas:
  - Expand ideas of individual-centered and family-centered support
  - Increase flexibility in rules for family members to provide services
  - Survey hobbies, interests, and/or values for potential roommates
  - Give first resident(s) a say in future resident(s) and live-in staff
  - Respect that integration might not be desired in all cases
- Increase diversity of options that respect personal preferences in housing and community of residence, including rural options. Examples:
  - Housing co-ops
  - Single occupancy homes
  - Housing specific for young adults ages 18-21
  - Work program that includes housing as part of compensation
- Increase housing resources to avoid long waitlists and financial supports.
- Raise public awareness of where people go to get access to resources for housing.
- Provide more specialized housing to address acute and specific complex needs, including transitional housing and more long-term assisted living facilities.

Advocacy

"…lack of knowledge by the public and governmental entities…and economic barriers such as the limitations on income earned while on SSI/SSDI that thoroughly discourages employment has left persons with disabilities the most discriminated against class in our society." – Survey Comment

What is the vision of the future for Advocacy?

Public Awareness & Accessibility

- **Awareness of the needs of people with disabilities leads to greater accessibility, the removal of physical and attitudinal barriers.**
- **People with disabilities are actively included and respected as important members of the community.**

Self-Advocacy

- **A strong self-advocacy system for people with disabilities enables them to speak up for themselves, beginning at an early age.**
- **People with disabilities have safe places and support to learn to speak up for themselves.**
- **The right to make choices, express desires, and express opinions is valued and respected.**
- **Adults with disabilities assume leadership roles and are involved in policy development and cultural activities.**

Advocacy

- **There is unity in advocacy across agencies, types of disabilities, and across the lifespan.**
- **People without disabilities own their own biases and collaborate with individuals with disabilities without controlling them.**
- **Individuality is embraced.**

Civic Engagement & Policy

- **People with disabilities are knowledgeable about public policy issues and candidates running for public offices, and they vote.**
- **People with disabilities are involved in local government, participate in public forums, and are involved in decision-making processes.**
- **Public and court officials are educated and informed about people with disabilities, their rights, and their desires to be included.**
- **There is equality under the law and due process for all people with disabilities.**

What are priorities for Advocacy?

The first priority in Advocacy is for the choice, desires, and opinions of individuals to be valued and respected (39%), followed closely by greater public awareness and accessibility (38%), and unity in advocacy across agencies, types of disabilities, and the lifespan (34%). Table 4 shows the total response.

Table 4: Priorities in Advocacy

Rank	Priority Statement	%Response
1	Choices, desires, and opinions valued and respected	39%
2	Greater public awareness and accessibility	38%
3	Unity in advocacy across agencies, types of disability, and lifespan	34%
4	Public and court officials know about disabilities	30%
5	Improved attitudes of advocates, working together without controlling	27%
5	Safe places and support to learn self-advocacy	26%
6	Strong self-advocacy system	26%
7	Involvement in local government, public forums, decision making	22%
8	Leadership roles in policy development and cultural activities	21%
9	Equality under the law and due process	20%
10	Participation in public policy and voting	11%
	Total Respondents: 273	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

What strategies were suggested for Advocacy?

Strategies for Public Awareness & Accessibility

- Use social media and other educational means for cultural change to promote respect and understanding of people with disabilities.
- Assist development of health networks in rural areas to integrate services.
- Work on moving away from the negative and deceptive label “disabled” which sets people up to be in a “have not” category.
- Look for national leaders among people with disabilities to act as spokespersons working to change prejudiced opinions.
- Help the public to recognize and respect invisible disabilities.

Strategies for Self-Advocacy

- Ensure people have a voice in developing their plans (Individualized Education Program-IEP, Plan of care, treatment plan…etc.).
- Foster support networks such as Peer Power, Partners in Policymaking, and People First.
- Use social media to advocate and teach appropriate ways to respond to cyber bullying and other bullying behavior.
- Teach self-advocacy skills, starting from an early age. Ideas:
  - Include it in the IEP, parent-teacher conferences, and team meetings
  - Use a self-advocacy curriculum in school including resources/tools
  - Teach people how to speak up for oneself
  - Allow risk taking and learning from mistakes
  - Provide opportunities to build self-esteem and confidence
  - Help people learn about their disability, strengths, and needs
  - Educate about disclosure (benefits, drawbacks, when to disclose)
  - Teach people how to listen
  - Use role-play to teach people how to be a self-advocate

Strategies for Advocacy

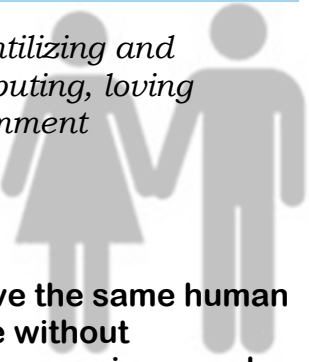
- Make resources, tools, and education available to promote advocacy and self-advocacy for others.
- Train families and staff to support self-advocacy and keep the individual's beliefs and values in the forefront.
- Facilitate opportunities to self-advocate and celebrate everyday self-advocacy successes for individuals of all ages.
- Build relationships between seniors (e.g., AARP, Senior Centers) and people who experience a variety of disabilities (e.g., Brain Injury Network, physical disabilities) to advocate for government policies, funding, resources, and services.
- Provide incentives to family members and care providers to get involved in advocacy groups.

Strategies for Civic Engagement & Policy

- Conduct targeted advocacy to policy makers.
- Provide opportunities to learn about public policy issues and political candidates, attending political forums and town-hall meetings.
- Provide more resources for senior advocacy groups and organizations.
- Increase resources and assistance for filing complaints, and legal actions to enforce existing laws and regulations.
- Advocate for more non-partisan legislation and public policy that address issues related to housing and employment, equal accessibility in society and in the workplace.

Relationships

"Our assisted living homes are disgraceful in their infantilizing and warehousing of people who could be working and contributing, loving and breaking up like everyone else." –Survey Comment



What is the vision of the future for Relationships?

Inclusion & Human Rights

- It is taken for granted that people with disabilities have the same human needs and desires for healthy relationships as people without disabilities, including friendships, sexual relationships, marriage, and family.
- People with disabilities have the right to be treated with respect and dignity at every stage of life, with the same basic human rights afforded to people without disabilities.
- At every stage of life, all people are safe from abuse and neglect, prejudice, exploitation, and violence in every social environment, including homes, schools, neighborhoods, and communities.
- People with disabilities are included in the social patterns of life appropriate for each stage of life in school, work, and community, characterized by an interdependent network of support with a diversity of people, including family, friends, co-workers, and neighbors.

Access to Information & Supports

- Education about healthy relationships, covering a full range of knowledge, skills, and safety appropriate for each stage of life, is available to all people, including people with disabilities.
- Supports for people with disabilities encourage and assist with the development and maintenance of healthy relationships appropriate to each stage of life, including friendships, sexual relationships, marriage, and parenting, always respecting the dignity of the individual and the balance of choice, risk, safety, and privacy.

Choice

- People with disabilities have the same rights as other people to make choices in their social and relational lives based on their own exploration of self, in the context of the social, family, moral, cultural, and religious mores they choose to guide them.
- Supports for people with disabilities foster healthy choices in relationships by offering a diversity of safe and inclusive social opportunities in contexts appropriate to each stage of life, respecting the boundaries of privacy and each individual's rights.

Policy & Regulation

- Policies and their alignment with funded supports fully allow for and support the same social and relational choices for people with disabilities as enjoyed by people without disabilities, including marriage and housing options that support choices in relationships.
- Flexible supports are driven by a diversity of individual needs and priorities revised over time through each stage of life by people with disabilities and their families in consultation with professionals.

What are priorities for Relationships?

The top priority in Relationships is for safety from abuse, violence, unfair treatment, and exploitation chosen by 70% of respondents. The second highest is for flexible supports driven by individual needs and priorities (46%), followed by staff respect for the dignity of risk, boundaries, and the balance among individual choice, safety, and privacy (43%). Over a third of respondents (35%) also chose recognition for equal human needs for healthy relationships and equal human rights. Table 5 shows the total response.

Table 5: Priorities in Relationships

Rank	Priority Statement	%Response
1	Safety from abuse and violence, unfair treatment and exploitation	70%
2	Flexible supports driven by individual needs and priorities	46%
3	Staff respect the dignity of risk, boundaries, and the balance of choice, safety, and privacy	43%
4	Equal human needs for healthy relationships and equal human rights are recognized	35%
5	Network of natural supports that help each other	28%
6	Inclusive education about healthy relationships	25%
7	Right to make choices based on self-exploration	14%
7	Policy allows for equal social and relationship choices	14%
8	Included in social patterns of life	13%
9	Policy includes incentives for marriage	4%
	Total Respondents: 268	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

What strategies were suggested for Relationships?

Strategies for Inclusion & Human Rights

- Make information/education for developing skills in human relationships, appropriate to each stage of life, readily available for everyone.
- Provide integrated opportunities to practice and develop social skills appropriate to each stage of life, such as organized groups for play, peer support, and dating.
- Educate the public about people with disabilities and their rights, dispelling myths and stereotypes. Ideas:
  - Incorporate education about disabilities in the K-12 curriculum for all students
  - Utilize media resources
  - Support self-advocacy and seek out venues for people with disabilities to have a public voice
  - Utilize role models
- Integrate people with disabilities in the social patterns and environments of life, fostering family, peer, and community relationships. Examples:
  - Preschool and childcare
  - Summer camps
  - Primary, secondary, and post-secondary education
  - Social gatherings
  - Community events
  - Faith-based activities
- Provide education and support for caregivers to encourage and foster social relationships for children, teens, and adults with disabilities. Ideas:
  - Plans for attending social and community events
  - Peer partner clubs
  - Peer support for dating
- Provide supports for communication (e.g., assistive technology).
- Increase effectiveness of response to reports of harm committed by care providers.

Strategies for Access to Information & Supports

- Utilize appropriate resources to make education about developing healthy relationship accessible to people with disabilities. Ideas:
  - Friendship and Dating groups
  - Training in social-emotional and communication skills

- Venues to role play and practice developing social skills in different social environments
- Sex education curriculum that is the same as or adapted from what is used for everyone

- Ensure education covers:
  - Safety, avoiding violence, disease, toxic relationships, and reporting abuse/neglect
  - Healthy relationships, boundaries, responsibilities, and the dynamics of relationships over time, particularly what is relevant to dating and marriage
  - Consequences relevant to pregnancy, birth, and parenting
- Provide training for caregivers and providers in encouraging, fostering, and supporting healthy relationships. Ideas for training topics:
  - Normalizing healthy human relationships for people with disabilities at every stage of life
  - Openly communicating about healthy relationships, including the general and personal consequences relevant to pregnancy, birth, and parenting
  - Setting goals for a diversity of healthy relationships at every stage of life (Individualized Family Support Plan-IFSP, Individualized Education Program-IEP, Plan of Care, etc.), including planning for supports for pregnancy, birth, and parenting
  - Utilizing existing resources, such as the Special Education Service Agency (SESA), pediatricians, and other healthcare providers
  - Respecting human rights and personal choices, and appropriately deal with conflicts with one's own values, culture, and beliefs
  - Allowing time for relationships, and respect privacy, particularly regarding intimate relationships and what is documented in records
  - Awareness of trauma and its impact on social relationships, trauma-informed services and supports
- Provide supports for healthy relationships in families, especially in rural areas.

Strategies for Choice

- Focus advocacy and self-advocacy efforts on respecting and enforcing the rights of individuals with disabilities regarding choices in their social and relational lives, based on the beliefs and values they choose to guide them.
- Create safe spaces where people with disabilities can have open dialogues about relationships and get answers to their questions.

- Foster safe and informed access to the same relationship resources used by peers without disabilities, including technology and online relationships.
- Train and support self-advocates to stand up for their rights to have the means to develop healthy relationships at every stage of life.
- Encourage flexibility for healthy relationships in more restricted housing (e.g., assisted living homes) to allow for privacy and intimacy.

Strategies for Policy & Regulation

- Reform regulations so that they support choices in healthy relationships without disincentives or penalties (e.g., marriage, housing options that support healthy relationships).
- Provide funding for fostering healthy relationships, including access to the social spaces appropriate to each stage of life.
- Incorporate more flexibility in supports so they encourage rather than restrict choices in social activity. Examples:
  - Do not restrict meals to in the home
  - Increase discretionary funds

Economic Wellbeing

"A disabled person has little or no incentive to even try returning to the workforce when they are punished financially…for making the effort. Without a continuing, absolutely reliable source of medical care, my life is in danger." –Survey Comment

What is the vision of the future for Economic Wellbeing?

Families & Children

- Families have economic stability (e.g., employment, childcare, consistency of services and care).
- Parents receive education and support to foster their child's economic self-sufficiency beginning in early childhood.
- Doctors, therapists, and schools provide information about resources and supports for economic wellbeing.

Adolescents & Working-Age Adults

- Employment is an expectation and individuals exiting school have vocational skills and the same opportunities as those without disabilities to succeed.
- Individuals with disabilities have opportunities for career exploration and career ladders, with choice in goals for income, spending, and independent living.
- There are no system gaps, and individuals receive adequate support to transition to young adulthood, including supports for overall money management.
- Long-term planning is in place to assure economic wellbeing across the lifespan, including plans for when parents or guardians pass away.
- Adults with disabilities have meaningful employment in a career of their choice, in inclusive settings that provide natural supports and if desired, opportunities for positive relationships with co-workers.
- Individuals with disabilities have opportunities to work full time, earn a living wage, receive benefits, advance in careers, and become less dependent on SSI/SSDI (Supplemental Security Income/Social Security Disability Insurance).

Seniors

- Economic wellbeing extends across the lifespan, and seniors with disabilities have financial security and medical benefits.
- Seniors have choice and independence, including options that allow them to stay in their homes/communities and age in place.

- Seniors have access to employment, volunteer work, social events, and leisure/fun activities.

Community Awareness & Involvement

- The community recognizes the value of employees with disabilities.
- Employers see individuals with disabilities as having a positive impact on business and are willing to provide reasonable accommodations and flexibility.

Policy & Regulations

- Policy supports economic wellbeing and security across the lifespan, and economic wellbeing is defined from an individual perspective.
- Employment in the general workforce is a first and preferred outcome in the provision of publicly funded services for all working age citizens with disabilities, regardless of level of disability.
- Policy and practice support seamless services without gaps, and flexible supports during life transitions.
- Policy does not penalize individuals for gaining employment (e.g., no loss of benefits, stipends, healthcare).
- Minimum wage laws apply to people with disabilities, and they receive equal pay for equal work.

What are priorities for Economic Wellbeing?

The subsection Economic Wellbeing Across the Lifespan included the main ideas from three themes: 1) Families & Children, 2) Adolescents & Working-Age Adults, and 3) Seniors. The priority that rose to the top is long-term planning for economic wellbeing across the lifespan (47%). This is followed by opportunities to work full-time and earn a living wage (34%) and equal opportunity for job skill development and career exploration (33%). Table 6 shows the total response.

Table 6: Priorities in Economic Wellbeing Across the Lifespan

Rank	Priority Statement	%Response
1	Long-term planning for economic wellbeing across the lifespan	47%
2	Opportunities to work full-time and earn a living wage	34%
3	Equal opportunity for job skill development and career exploration	33%
4	Choice in goals for income, spending, and independent living	29%
5	Meaningful work in career of choice	28%

Rank	Priority Statement	%Response
6	Resources for parents to teach their children to be self-sufficient	27%
7	Doctors, therapists, schools provide information about resources/supports	23%
8	Employment is expected	21%
9	Supports for overall money management	20%
10	Opportunities that include benefits and career advancement	16%
11	Inclusive settings with natural supports	12%
	Total Respondents: 271	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

The subsection Economic Wellbeing Awareness & Policy included the main ideas from two themes: 1) Community Awareness & Involvement and 2) Policy & Regulations. There was a small set of statements and only one choice was allowed per respondent. The top priority is to have no penalties for gaining employment (38%). Table 7 shows the total response.

Table 7: Priorities in Economic Wellbeing Awareness & Policy

Rank	Priority Statement	%Response
1	No penalties for gaining employment (loss of benefits, stipends, healthcare)	38%
2	Community and employers recognize the value of employees with disabilities	31%
3	Seamless services and flexible supports	12%
4	Employers provide accommodations and flexibility	10%
5	Adequate support for transition	8%
	Total Respondents: 267	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

What strategies were suggested for Economic Wellbeing?

Strategies for Families & Children

- Utilize parent-to-parent support.
- Start using assistive technology, and other technology resources early.
- Start including job exploration and employment as an expectation in early childhood education.

- Utilize thread (project of the Alaska Dept. of Health & Social Services helping to connect families to inclusive childcare).
- Educate doctors, therapists, and schools about resources and supports.
- Assign chores and home responsibilities to children in order to develop basic employment skills and a work ethic.
- Provide training for parents in economic long-term planning options (e.g., living trusts).

Strategies for Adolescents & Working-Age Adults

- Build stronger relationships with employers.
- Educate employers and co-workers on providing accommodations and support.
- Utilize peer training and mentoring programs (e.g., partners programs, team programs, buddy system).
- Provide more resources for rural areas and villages and utilize creative strategies for places where employment opportunities are limited.
- Provide opportunities for lifelong skills building and education.
- Utilize web-based training for teachers and service providers.
- Blend arts with service provision and community (e.g., collaborative employment, working artist, storytellers, musicians, dancers, production).
- Utilize strength-based assessment and planning.
- Develop better models of direct support for self-directed work.
- Increase use of technology.
- Provide access to financial planners and budgeting support. Examples:
  - Benefits analysis
  - Work incentives
- Provide training and assistance to help avoid financial exploitation of people with disabilities (e.g., from individuals, scams, false business opportunities).
- Increase use of job carving.
- Provide a range of options because not everyone has the same needs (e.g., self-employment, supported employment, co-ops, online).
- Increase access to a high school diploma, and focus more on transition to postsecondary education and employment.

Strategies for Seniors

- Provide information about age- and stage-appropriate resources and counseling.
- Provide education about money management.
- Increase funding for services (e.g., meals on wheels, transportation).
- Provide more access to assistive technology.
- Examine Affordable Care Act for preventive medical services and education.
- Use natural supports.

Strategies for Community Awareness & Involvement

- Conduct community outreach to inform the public that people with disabilities can work (e.g., public service announcements, branding).
- Provide employer education on the benefits of hiring individuals with disabilities, including people with mental health disabilities.
- Engage employers and corporate partnerships (e.g., oil, gas, fishing, tourism industries) about adapting jobs and job carving for mutual benefit.
- Conduct inclusive employment job fairs.
- Provide public recognition for employers that do a good job of employing individuals with disabilities.
- Disability organizations should lead the way and model ideal practice (i.e., hire people with disabilities).

Strategies for Policy & Regulations

- Require better cooperation between support systems and avoid funding silos.
- Provide more transportation options (e.g., vouchers).
- Increase provider use of the Home & Community Based Waiver to provide employment services, including Ticket-to-Work, Medicaid Buy-In, work incentives, Individual Development Accounts, earned Income Tax Credit ($2,000) AARP, and student earned income exclusion.
- Provide incentives for getting people employed and fading to natural supports, rather than disincentives such as losing benefits (e.g., SSI, SSDI, Medicaid/Medicare).
- Provide financial incentives to employers that hire and provide accommodations for people with disabilities.
- Have a centralized database for resources.

- **Incorporate culture, community, lifestyle, and values in definitions of supported employment and meaningful work (e.g., to include subsistence).**
- **Reduce inefficiency in documentation, reduce redundancy and use technology to streamline paperwork.**
- **Examine the definition of "living wage" to include supporting healthy life choices (e.g., healthy diet, exercise, recreation, discretionary funds).**
- **Consider forgiveness of student loan debts due to economic hardship.**
- **Preparation for employment should be driven by an individual's goals and capacity rather than by the system's need to get people to work quickly in low paying jobs.**
- **Create more equity in the resources available to people with different types of disabilities.**
- **Pay special attention to the needs of veterans with disabilities.**
- **Allow for flexibility in supports that can follow changing situations, the ups and downs of life.**
- **Recognize the justified fear and anxiety people have around losing benefits, and that this stress impacts their health and wellbeing.**

Health

"We have two tiers of service, for rich and for poor. It would be helpful if it would be a crime to deprive care to people who need it."
–Survey Comment

What is the vision of the future for Health?

Quality of Healthcare

- Increased integration between providers results in better coordination and improved continuity of care.
- A team approach is used for the transition from pediatric to adult health services.
- There are improved professional standards and accountability for health professionals working with people with disabilities.
- There is better training for health professionals on working with individuals with disabilities and systems that support and incentivize those relationships.
- Health care is individualized, based on an individual's culture and strengths, with flexibility and adaptations by providers when needed.
- Providers consider the individual, not the individual's medical coverage, and do not deny care because of a disability.
- Insurance companies allow for choice of providers and more flexibility for time and coordination of care.
- Providers understand that the progression of age for seniors may be causing an issue rather than the disability.

Medication

- There is better overall management of medications including less overuse, less dependence, access to both Western and herbal medication, with information for decision-making that is accessible.
- Healthcare providers listen to individuals and their supports related to the effects and dosage of medication to find the best balance.

Wellness

- There is more accessible evidence-based preventative information for individuals, parents, and staff on topics like diet/nutrition, exercise, and stress management so all can work toward an environment supporting healthy choices.
- There is increased access to preventative screenings and immunizations/vaccinations.
- There is more community involvement in childcare to provide supports for working parents, including trained childcare providers.

- There are improved supports in rural Alaska for families to stay together in the community using natural supports (e.g., local churches) and technology to access health care providers.
- A holistic and comprehensive approach to health strives to improve overall quality of life through improvements to physical, social (e.g., relationships, intimacy, employment), emotional, and spiritual health.
- Physicians and other health care providers see the individual first and not the stigma of medical conditions.
- Disability is not seen as an illness, it is well known that people can be healthy and have a disability.
- There is more flexibility to use alternative medicine.

Choice

- Individuals are involved in setting health goals, creating support plans, and making health decisions.
- Individuals and their support teams are more educated with evidence-based information, and they share responsibility for health choices.
- Strong self-advocates that are empowered to have personal control over their health and environment, including the right to learn from mistakes.
- There are more providers doing family practice and lifespan care so that individuals have more choices and are able to build quality relationships with their health care providers.
- Individuals with disabilities have the right to make choices about their healthcare and decisions about their bodies.

Access

- Health facilities are physically accessible, information is presented in plain language, and transportation to services is readily available.
- There are more providers in key fields like dentistry, vision care, and family medicine to provide care across the lifespan.
- There is increased access to affordable quality healthcare and preventative screening/health maintenance services, where individuals are not treated differently because of disability.

Policy & Regulations

- Policies support care-driven (not cost-driven) services that include flexibility in how needed services are funded.
- Policies promote integration of healthcare and health promotion (social/emotional/spiritual health).
- Policies support use of standard and holistic medicine, with payment and access to both.

What are priorities for Health?

The subsection Quality of Healthcare included the main ideas from two themes: 1) Quality of Healthcare and 2) Medication. The top priority is for coordination and continuity of care among providers (46%). This is followed by providers are trained to work with individuals with disabilities (42%), and services are individualized and flexible (35%). Table 8 shows the total response.

Table 8: Priorities in Quality of Healthcare

Rank	Priority Statement	%Response
1	Coordination and continuity of care among providers	46%
2	Providers are trained to work with individuals with disabilities	42%
3	Services are individualized and flexible	35%
4	No denial of care because of a disability or medical insurance	28%
5	Team approach for transition from child to adult services	26%
6	Insurance allows for choice of providers, flexibility, coordination of care	25%
7	Providers see individuals first, not medical conditions	22%
8	Coordinated medication management	16%
9	Systems support and reward working with people with disabilities	14%
10	Improved professional standards and accountability	14%
11	Providers listen when making medication decisions	12%
12	Individuals are informed and have access to medication choices	10%
	Total Respondents: 269	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

The subsection Health & Wellness included the main ideas from two themes: 1) Wellness, and 2) Choice. The top priority is for a whole person, quality of life approach (66%). This is followed by a focus on wellness and prevention (54%), and for individuals and teams to share responsibility for choices in health goals, plans, and decisions (35%). Table 9 shows the total response.

Table 9: Priorities in Health & Wellness

Rank	Priority Statement	%Response
1	Whole-person, quality of life approach	66%
2	Focus on wellness and prevention	54%
3	Individuals and teams share responsibility for choices in health goals, plans, and decisions	35%
4	Access to meaningful activities	29%
5	Providers understand that people can be healthy and have a disability	27%
6	More flexibility for alternative medicine	25%
7	Right to learn from mistakes	21%
8	Natural and technology supports for families in rural Alaska	19%
9	Community investment in family wellness	17%
	Total Respondents: 267	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

The subsection Health Access & Policy included the main ideas from two themes: 1) Access and 2) Policy & Regulations. This was a smaller set of options and respondents were allowed to choose up to two ideas. The top priority is for affordable quality healthcare (50%), followed by policy supporting care-driven services (37%). Table 10 shows the total response.

Table 10: Priorities in Health Access & Policy

Rank	Priority Statement	%Response
1	Affordable quality healthcare	50%
2	Policy supports care-driven (not cost-driven) services	37%
3	Accessible buildings, information, and transportation	32%
4	More providers in dentistry, vision, and family practice	30%
5	Policy promotes integration of healthcare and health promotion	22%
5	Policy supports payment and access to both standard and alternative medicine	22%
	Total Respondents: 266	100%

Note: The number of respondents varies in the tables reporting prioritization results because participants were given the option to skip questions they chose not to answer.

What strategies were suggested for Health?

Strategies for Quality of Healthcare

- Increase education in healthcare provider training programs (e.g., disability, culture, lifespan, sensitivity, myths and stereotypes).
- Provide training to reduce discrimination and improve attitudes toward elders in the healthcare system.
- Allow more flexibility so doctors can take the time they need to work with individuals with disabilities.
- Healthcare providers need to talk to individuals with disabilities about what is going on and include them in decision-making.
- Provide care in the home environment when possible and appropriate.
- Physicians should work as part of team with input from patients and family/team members.
- Increase medical case managers.
- Look for good matches of staff, supports, and doctors who can positively impact health.
- Increase research in disabilities and aging.
- Provide better screening for dementia.
- Increase access to diagnostic equipment.
- Provide cross training for hospice.
- Provide more end-of-life education, as well as grief counseling for staff, families, and peers.

Strategies for Medication

- Improve medication management, including regular centralized review of medications, considering alternatives to medications, interactions, effects, and cost.
- Advocate for less medication use in foster care.
- Healthcare providers can present options, then the individual and their supports can make a team decision.
- Educate the individual, parents, team, and staff on the medications being used, the benefits and side effects, and general health maintenance.
- Provide access to a central database of medications and side effects.
- Develop practical solutions to situations needing nursing support (e.g., insulin injection, anticonvulsants, suppositories).

Strategies for Wellness

- Utilize Healthy Families America (or similar programs).
- Utilize the Wise Women Program from the Centers for Disease Control & Prevention (CDC) (e.g., prevention/screening for heart disease and stroke for the underinsured).
- Provide parenting classes specific to parents with children with disabilities.
- Create evidence-based wellness programs for parents, staff, and individuals (e.g., nutrition/diet, exercise, stress management).
- Allow people to choose a faith-based approach.
- Support the family unit to meet the needs of children.
- Provide resources for respite.
- Promote volunteering (e.g., Big Brothers/ Big Sisters, Partners programs).
- Use a holistic approach to transition and discharge planning.
- Promote inclusion in sports, clubs, and drama.
- Include mental health as component of total health plan.
- Provide training and information on behavioral supports.
- Provide access to resources to enhance relationships to support social/emotional health.
- Use talking circles to reduce stress and increase mental health, allowing children to feel honored, to learn from peers, and to normalize.
- Provide access to sex education for individuals with disabilities, explain hormones and what it means for the individual.
- Provide developmental appropriate support for life stage transitions.
- Provide education for individuals on how to not be a victim of abuse, neglect, and financial exploitation.
- Ensure meal programs provide healthy choices; consider local produce, fresh and dried fruit.
- Increase access to health clubs.
- Focus more on overall quality of life and individual goals and choices to improve health.

Strategies for Choice

- Reduce institutionalization by promoting social/physical/emotional wellbeing.
- Make tools available for motivation/education, which explain the health risks and benefits of choices.

- Provide a centralized scientific evidence database on a State website with information on diseases/treatment concerning development disabilities.
- Provide education in healthy choices (e.g., eating right, physical activity, going to the doctor, hygiene), and provide more accessible tools for providers and parents in how to teach these skills.
- Provide access to information on contraceptives, including their benefits and risks.
- Provide training in creating a Personal Wellness Plan.
- Provide access to information and services to manage life-changing issues (e.g., dementia, Alzheimer's).
- Support Health Navigators.
- Include Direct Service Providers and natural supports in planning meetings.
- Liaison to help families communicate (discuss options).
- Encourage transparency of information about choices related to medical procedures.
- Use role models to model healthy choices and healthy decision-making.
- Involve kids early so they understand their own medical needs.
- Provide self-advocacy training.
- Provide education about individual rights.
- Provide information for families and care providers to navigate when choices conflict with safety.
- Use more of a team approach in patient advocacy, where the team decides what is best. Examples
    - Writing letters to insurance companies
    - Making phone calls needed for care
    - Fighting with Medicaid
    - Hospital stays
- Use Assistive technology to increase the ability of individuals to communicate their choices.

Strategies for Access

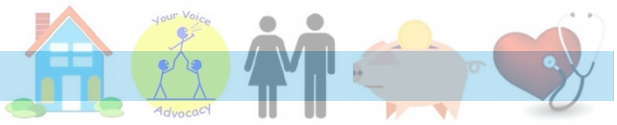
- Use technology to increase access (e.g., rural communications)
- Provide interpreters.
- Ensure wheelchair accessibility in health facilities.
- Allow for doctor home visits.
- Fix technology gaps.

- Stop using "rural" as an excuse.
- Make sure people with intellectual and developmental disabilities have access to mental health services.
- Ensure people know where to go to find out about available resources and services (e.g., itinerant specialists).
- Find resources to help make health facilities accessible.
- Ensure bus routes go to commonly used health facilities.

Strategies for Policy & Regulations

- Promote a national health insurance policy for a tax credit.
- Reimburse physicians for various types of services (i.e., not just for face-to-face visits).
- Redefine disability in policies so that disability doesn't mean healthcare.
- Mandate pre-natal check-ups for people using publicly funded services.
- Lower eligibility requirements for early intervention.
- Ensure Medicaid/Medicare covers:
  - Dental services
  - Mental health services
  - The cost of nursing services required for medication administration
  - Preventive healthcare
  - Alternative medicine and therapies (e.g., light therapy for Seasonal Affective Disorder)
- Provide better coverage and access for people in rural communities by Medicaid/Medicare (e.g., travel problems, no flights, can't drive).
- Address Medicaid barriers like service codes.
- Fund a forum for people to talk about and receive training in health promotion.
- Provide for more oversight and support for nursing staff to manage stress and to deal with loss when patients die.
- Provide debt forgiveness programs for providers that make serving individuals with disabilities a priority.
- Increase providers in dentistry, vision, family practice, behavioral health, and other specialties, and provide incentives for them to serve people with disabilities.
- Reduce disincentives and increase incentives for more providers to accept Medicaid/Medicare.
- Ensure insurance compensates providers fairly and in a timely manner.

Universal Themes



"I would like to see our children with this disability have the same chance to be like the rest of the 'normal world.'"–Survey Comment

What improvements could have impact across areas?

There were issues that crossed all topical areas in the summit and thus can be considered universal themes. As will be seen in the following discussion of how these issues came up in each area, they are highly interrelated and relevant to quality of life. It can be concluded that considering these issues and making improvements whenever possible could have broad impact.

Transportation

- **Housing Arrangements: Transportation was brought up frequently as a critical issue relevant to housing. Participants expressed needs for more transportation options and more expansive systems of transportation. It was noted that location of housing needed to consider closeness to accessible transportation, and distance from grocery stores, shopping centers, food banks, and shelters. Transportation was also a factor in making community activities accessible.**
- **Advocacy: Lack of accessible transportation was noted as a physical barrier to people with disabilities, increasing the negative impact of a disability and preventing or limiting participation in all dimensions of community living.**
- **Relationships: Access to transportation was noted as critical to preventing social isolation. It was noted as necessary for accessing information and supports for developing healthy relationships, as well as for participating in social activities. Independent access to transportation was noted as a factor to facilitate freedom of choice and privacy in relationships that people without disabilities take for granted.**
- **Economic Wellbeing: Individual access to reliable and consistent transportation was noted as crucial to economic wellbeing, particularly in adolescence and continuing across the lifespan. It was noted as essential for the ability to successfully hold down a job, and to participate in volunteer and leisure activities. One survey respondent noted that the ability to be punctual is often a factor in whether or not an employer will choose to hire the person with a disability or another applicant for a job.**
- **Health: Reliable transportation was noted as a necessity for getting to and from medical appointments and wellness activities within time constraints. For more rural communities, it was noted that reliable and affordable transportation extended to travelling to more urban communities to access necessary services.**

Inclusion

Something mentioned periodically by people in the summit and in survey comments was that not every person with a disability wants the same things or has the same capacity. This particularly came up in talking about issues relevant to inclusion. It is worth reminding readers of this report that the population of people with disabilities is highly diverse. Inclusion is about removing societal or systematic barriers that single out and exclude people with disabilities. What a person might choose is dictated by unique personal goals, values, and desires, as well as strengths and limitations.

- Housing Arrangements: Inclusion was expressed as a need for more housing options that are fully integrated with other people in the community, and to be included in community activities. It was noted that all people should have the option to spend time with their peers across the lifespan – with other children, adolescents, adults, and seniors. Considerations mentioned for location of housing included proximity to schools, spaces for meeting, and inclusion in emergency preparedness.
- Advocacy: Inclusion was largely addressed in the context of being involved in the decisions that impact one's own life, to be invited to the table for policy development, and to be considered for government, community, and cultural leadership roles.
- Relationships: Inclusion was addressed in the context of human rights in relationships. Participants noted fears and stigmas as barriers to accessing the same social activities as other people. It was noted that more natural supports from peers might better facilitate social inclusion.
- Economic Wellbeing: Inclusion was addressed in terms of being able to participate with other people in activities and opportunities related to improving access to employment. This included expectations for education and employment, and participation in job/career exploration, internships, and volunteer opportunities. It also included access to the same technology resources as peers.
- Health: Inclusion was addressed in the context of wellness, such as inclusion in sports, clubs, and drama activities. It was also addressed in the context of the respect that is afforded to other people to be informed and to be included in decisions about medications, approaches to healing (e.g., holistic, alternative, traditional), and personal health behaviors.

Advocacy

Advocacy was a topic of the summit with focused attention on its own merits. Those results were covered earlier in this report. However, advocacy was also brought up under other topics in the context of strategies. Generally, advocacy as a strategy was relevant to both self-advocates and other advocates.

- **Housing Arrangements:** Advocacy was noted as a strategy to increase housing opportunities for people with disabilities so that they have choices like other people about where they live and with whom.
- **Relationships:** Advocacy was noted as a strategy to ensure people with disabilities have a voice. Awareness for parents could enable them to advocate for the rights of their children with disabilities to participate in summer camps, both day camps and overnight camps. Another specific strategy was supporting self-advocates to educate the public about people with disabilities, to dispel the myths and stereotypes that are barriers to their participation in the social fabric of the community.
- **Economic Wellbeing:** Advocacy was noted as a strategy to increase the services necessary to facilitate economic wellbeing across the lifespan, to inform the public and employers about the value and contributions of people with disabilities, and to develop partnerships in the community to increase opportunities for employment of people with disabilities.
- **Health:** Advocacy was noted as a strategy to help address the long list of issues related to improving the quality of healthcare and access to healthcare. It was noted as a specific strategy to help reduce overuse of medication in foster care. Helping people understand healthcare, their needs and options, along with self-advocacy training was a specific strategy to enable people to make choices about their own bodies. Patient advocacy was also mentioned in the context of a team approach to making health and healthcare decisions.

Equality

- **Housing Arrangements:** Equality was brought up in the context of being considered equally valued in interdependent relationships among fellow residents in neighborhoods. It was also addressed in having individual and family housing options equal to peers who are not dealing with disabilities.
- **Advocacy:** Participants expressed a need to advocate for people with disabilities to have equality under the law with people who do not have disabilities, with equal access to due process.
- **Relationships:** Equality was framed as an issue of human rights in the context of relationships. Participants expressed a need for people with disabilities to receive the same respect and dignity afforded to other people, including the right to explore their own values and beliefs, and to be supported in making their own choices in friendships, romantic relationships, and marriage.

  An issue that came up in relationships, and also in the next two topical areas was the right afforded to people in U.S. culture to take risks and to make mistakes, and consequently to learn from their own successes and failures. Participants voiced this as something that is taken for granted for everyone else, but often denied to people with disabilities

- **Economic Wellbeing:** Equality was mostly an issue of access to the same educational and experiential opportunities designed to prepare people for economic security. It included giving families an equal voice in setting goals and making plans for the future economic security of their children.
- **Health:** Equality was an issue of both rights and access in the context of health. Participants did not want life and health denied to people because they have disabilities. They wanted to see equal access to treatment, preventive services, health education, and wellness activities. This included equal access to faith-based and alternative medicine approaches.

Accessibility

- **Housing Arrangements:** Accessibility was brought up frequently in the context of housing. Participants asked for both more accessible homes and more ability to make homes accessible. Universal Design was brought up as a specific strategy for the former, while it was noted the latter would need more landlords willing to allow modifications, as well as more resources to make modifications. Accessibility was also discussed in the context of a need for increased participation in the community, making more places and activities accessible to people with disabilities.
- **Advocacy:** It was noted that utilizing advocacy to increase public awareness about people with disabilities could help encourage increased accessibility across the community.
- **Relationships:** In the context of relationships, accessibility was largely addressed in terms of making existing curriculum and information resources accessible to students with disabilities, so they could participate in the same classes and use the same resources as their peers. This included health and sex education in schools and using technology-based social resources.
- **Economic Wellbeing:** Accessibility was largely addressed in terms of making existing activities in schools aimed at future employment accessible for students with disabilities. For adults, it was making employee assistance programs and financial planning resources accessible to people with disabilities.
- **Health:** In the context of healthcare, it was noted medical and service facilities needed to be more accessible. It was also noted medical information needed to be more accessible so people with disabilities could make informed decisions. Examples were information about medications, contraceptives, and conditions related to aging. Similarly in the context of wellness it was noted that health clubs and churches needed to be more accessible, as well as wellness information on topics such as diet and nutrition.

Choice

- Housing Arrangements: People mentioned needs for more diverse options for housing, including choices of where to live, who to live with, and routines. It was noted that personal perspectives based on individual values, goals, family, and culture should be respected, and that there should be flexibility in funding to accommodate reasonable choices.
- Advocacy: In discussions around advocacy, choice was an issue of freedom – the freedom to make choices, to express desires and opinions, and to have them respected whether or not others agreed with them. A specific issue mentioned was the freedom to choose how to eat, particularly a healthier diet, often denied to people in assisted living.
- Relationships: Choice was about the freedom to choose relationships, particularly romantic relationships, based on one's own values and desires, not controlled by the opposing values and desires of others or restricted by regulations. It was also an issue in social activities, choosing where to go to meet people. It was acknowledged that choice and privacy had to be balanced with risk and safety, but people wanted to see more freedom to make choices in relationships like what is afforded to peers without disabilities, including the opportunity to learn from bad choices.
- Economic Wellbeing: In discussing economic wellbeing, choice was largely an issue relevant to developing a career. This included access to resources for early preparation. It was noted that the system should support career development based on individual capacity and choice, allowing more time for training or education as appropriate. It was also noted that a choice to stay in one's own home and age in place might well be a factor in economic wellbeing.
- Health: Choice was an issue integral to every aspect of health – being able to choose providers and approaches to health and healing. Spiritual and cultural approaches were mentioned, in addition to alternative medicines and therapies, prevention services, and wellness goals and activities. Access to understandable and transparent information, and flexibility in funding were essential for the ability to make choices.

Flexibility

- Housing Arrangements: Flexibility in regulations and licensing was noted as essential to having real choices in housing, to include people in the community, accommodate personal preferences, and to respect cultural values.
- Advocacy: The concept "dignity of risk" was noted as a general advocacy issue for quality of life, the flexibility to allow for reasonable risks.
- Relationships: In relationships, flexibility was noted in the context of the supports provided to people with disabilities, responding to the diversity of

individual needs and priorities, and recognizing that needs and priorities change over the course of a person's life.

- Economic Wellbeing: Flexibility was discussed both in terms of system supports and from the perspective of employers. This included flexibility in supporting different types of work that might not fit the usual mold, as well as flexible workplace policies to accommodate differences. One specific example for flexibility in the system was to allow people to keep benefits when work is temporary in nature, such as seasonal work.
- Health: In healthcare, it was noted there needed to be flexibility to provide care on an individualized basis, considering a person's values and beliefs as well as strengths and limitations. This included making adaptations and spending more time with people, as well as more flexibility in how a person's healthcare is funded. It included flexibility in funding to allow for diverse approaches, including alternative medicine.

Safety

- Housing Arrangements: Safety was a major topic of discussion in housing, particularly in consideration of where housing is located. Safety and stability were often mentioned together. It was acknowledged this might not mean the same thing to every individual or be the same for every stage of life. Safety was discussed in a community context, such as finding ways for community members to work together on making neighborhoods safe for all residents.
- Advocacy: It was noted in discussions of advocacy that people are safer when they are known. It was mentioned that people need safe places to learn about advocacy, and safe avenues for speaking up.
- Relationships: Safety was a big issue in discussions about relationships. It was noted as critical for people to be safe from abuse and exploitation. However, the "dignity of risk" was a particularly salient issue, calling for a balance among safety, choice, risk, and privacy in relationships. Safety was brought up frequently in the context of training/education for people with disabilities. "Safe spaces" were mentioned for learning, asking questions, and for socializing with others.
- Economic Wellbeing: It was noted a person needs economic stability to be safe. It was connected with safety in housing and relationships.
- Health: It was noted that sometimes people make choices in health and wellbeing that conflict with safety, and there is a need for better guidance for families and care providers to navigate this situation.

Public Awareness

Public awareness crossed all topical boundaries as a need for promoting general acceptance and respect for people with disabilities. It was mentioned frequently in the context of reducing stigmas, fears, prejudices, stereotypes, and myths. It was also noted for avoiding apathy and antipathy.

- Housing Arrangements: Public awareness was mentioned in terms of improving attitudes toward people with disabilities living in the community.
- Advocacy: Public awareness is a core purpose of advocacy. More specific strategies to promote public awareness included using publicity, social media, and cultural champions.
- Relationships: Public awareness was relevant to relationships in promoting the acceptance of people with disabilities in social arenas.
- Economic Wellbeing: The need to educate the public was brought up by a number of people in discussions of economic wellbeing, particularly regarding the potential of people with disabilities to work and contribute to their communities.
- Health: In discussions of health, public awareness about people with disabilities was a means to increase awareness among the people who provide a variety of services in the community for everyone.